"IT'S EASY TO ASSUME THAT THEY'RE OKAY": GENETIC COUNSELORS' WILLINGNESS AND PREPAREDNESS TO DISCUSS THE INTERPERSONAL AND PSYCHOLOGICAL EFFECTS OF MISCARRIAGE

by

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Abstract

This exploratory study aimed to examine genetic counselors' perspectives on and practices related to the psychological and interpersonal effects of miscarriage. Miscarriage is frequently uncovered in genetic counseling sessions during the taking of a pregnancy history, and given that the genetic counseling profession places a high level of importance on psychosocial counseling, it is relevant to consider whether and how such information is discussed within the session. This study consisted of an online survey of 200 prenatal genetic counselors and semi-structured interviews with a subset of 25 genetic counselors recruited via the National Society of Genetic Counselors Listserv. The aims were to assess genetic counselors' perspectives on the psychological and interpersonal effects of miscarriage and their preparedness to discuss the effects. This study also aimed to identify the most pertinent barriers to effective discussion of the impact of miscarriage. On the whole, survey results indicate that genetic counselors have a strong appreciation for the psychological effects of miscarriage and feel prepared to discuss it. However, when taken in the context of the qualitative findings, the results suggest that genetic counselors may be unaware of or reluctant to admit the areas in which they feel less prepared. Overall, our findings indicate that a training intervention for genetic counselors may be warranted.

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Preface

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Introduction

It is estimated that between 8 and 20 percent of all known pregnancies end in miscarriage. As many as one in every four women will experience a miscarriage in her lifetime (Ford et al., 2009; Tulandi et al., 2016). Until a spike in research interest regarding the grief caused by miscarriage appeared in the 1990's, healthcare professionals typically regarded pregnancy loss as an event from which a woman was expected to recover quickly, and in general, women were not expected to experience lasting psychological consequences (Conway, 1991). As research in this area grows and evolves, new findings are being translated into clinical practice.

In a comprehensive review of the literature regarding the psychological effects of miscarriage, Lok and colleagues estimate that 40% of women experienced significant grief following the loss of a pregnancy (Lok et al., 2007). In a review of 22 studies (N = 2,485) that characterized grief after miscarriage using the Perinatal Grief Scale, it was found that both the intensity of grief and the duration of the grieving period after miscarriage were comparable to perinatal death (Toedter et al., 2001). While Lok and colleagues note that grief is a common and often normal adaptive process, it can potentially evolve into "pathological grief," a more serious psychiatric concern. Pathological grief is characterized by extended feelings of despair, hopelessness, worthlessness, and an inability to interact with others, leading to social isolation.

Miscarriage can also have more serious psychiatric effects. A study examining the depressive symptoms of 382 women following miscarriage reported that 36% of women demonstrated moderate to severe depressive symptoms six months after miscarriage.

Women who had experienced a miscarriage in the previous six months were 3.4 times as likely to demonstrate depressive symptoms than pregnant women ($N = 283$), and 4.3 times more likely than control women in the community ($N = 318$) (Neugebauer et al, 1992). Prospective studies have repeatedly demonstrated that women who experience miscarriage are more likely to experience depressive symptoms than women who have not (Janssen et al., 1996; Beutel et al., 1995; Lok et al., 2007, etc.).

Lok and colleagues report in their review that the rate of diagnosis of a depressive disorder varies widely between studies, ranging from 10 to 51% (Lok et al., 2007). This could be due to the fact that studies that have examined the relationship between miscarriage and depressive disorders have often utilized small sample sizes and lacked consistent diagnostic methods.

Research on development of anxiety disorders after miscarriage is more scarce. In one study, the prevalence of three anxiety disorders (obsessive-compulsive disorder [OCD], panic disorder, and phobic disorder), as diagnosed by the Diagnostic and Statistical Manual (DSM) criteria, was compared between 229 women who had experienced a miscarriage in the last six months and 230 women from the community. The relative risk of developing any of the three disorders was 1.5 comparing the miscarriage group to the control group, and the relative risk of developing OCD was 8.0 (Geller et al., 2001).

Studies have found complex and conflicting results regarding the relationships of couples who have experienced the loss of a pregnancy. Swanson and colleagues explored 242 women's perspectives of their interpersonal and sexual relationship with their partner

in the year following miscarriage. After one year, approximately 33% of women claimed that their interpersonal and sexual relationships were more distant than they had been before the miscarriage, and approximately 10% felt their relationships had grown closer. Relationships with greater distance were associated with more frequent anxious, angry, and depressed moods. These effects tended to be modified by women's perception of caring gestures from their partners; when women perceived that men did not perform caring gestures, they perceived greater distance in the relationship, and vice versa (Swanson et al., 2003).

These results starkly contrast those of DeFrain and colleagues' study of 193 individuals affected by miscarriage (172 mothers and 21 fathers). 61% of partners reported that their marriage was strengthened by the miscarriage because they found comfort in each other during distressing times (DeFrain et al., 1996). Further research into the variables that determine whether relationships prosper, deteriorate, or stay the same after miscarriage and more standard measures of relationship resilience are warranted. DeFrain also found a marked difference in the way male and female partners handle the distress of miscarriage; 74% of couples experienced a disagreement on coping methodology. In general, women tended to prefer to cope with the help of others, and men tended to cope alone.

The Perspective of the Male Partner

Little importance has been historically placed on the male partner's reaction to miscarriage. Inquiry into this subject largely began in the 1990's with several qualitative studies (e.g. Miron & Chapman, 1994; Puddifoot & Johnson, 1997.). These studies

suggest that the male response to miscarriage is extremely varied, covering a vast spectrum of emotions, appraisals, and responses. Interviews with eight men whose partner experienced a miscarriage reveal several prevailing patterns: many men experienced sadness, hopelessness, and anger immediately following the miscarriage, but these feelings were secondary to their concern for supporting their partners. Men often hid their emotional reactions from their partners in an attempt to protect their partners from becoming more upset (Miron & Chapman, 1994).

The Effect on a Subsequent Pregnancy

It has been estimated that as many as 50% of women who experience a miscarriage become pregnant again within the first year post-miscarriage (Forrest et al., 1982). Because of this, one of the most extensively studied effects of miscarriage is the potential effect of pregnancy loss on subsequent pregnancies. In a review of studies comparing anxiety levels in women pregnant after a miscarriage and woman pregnant for the first time, nearly all report that pregnant women with a history of miscarriage experience higher levels of anxiety during pregnancy (Geller et al., 2004). This is particularly important given the findings that stress and anxiety can lead to adverse pregnancy outcomes (Berle et al., 2005; Mulder at al., 2002). This presents an urgent need for maternal anxiety to be addressed by health care providers during pregnancy following a miscarriage.

The Healthcare Provider's Perspective

There has been significant research exploring healthcare providers' attitudes towards and knowledge about miscarriage (e.g. Gold, 2007; Engel & Rempel, 2016). A study of 174 physicians, nurses, midwives, and other healthcare providers aimed to identify trends in the attitudes and beliefs of healthcare providers towards miscarriage, as well as barriers to appropriate care. Although most participants agreed that miscarriage is a distressing event for women, there was significant discord on whether women who experience miscarriage should be advised to "move on with their lives" and whether miscarriage could be classified as a "normal" event (Engel & Rempel, 2016).

When asked if they felt prepared to support families after miscarriage, 86% of participants felt either "prepared" or "somewhat prepared" to do so, and 14% felt unprepared to support people in these situations. Perceived barriers to providing appropriate care were identified, including lack of appreciation for the emotional impact of miscarriage, lack of knowledge about the cause of miscarriage (which lead to blame being placed on the woman), and a lack of guidance in the form of hospital policy. 43% of respondents stated that no policies regarding miscarriage existed in their place of employment, and 21% were unaware whether any such policies existed (Engel & Rempel, 2016). These findings indicate a gap in medical care after miscarriage; healthcare providers know that miscarriage is distressing and they care about their patients' wellbeing, but due to lack of training, policy, and in many cases time and resources, they may be left unable to provide the most appropriate care.

The Present Study

The literature has repeatedly demonstrated that healthcare providers' actions surrounding perinatal death can have an immense impact on patients' psychological wellbeing. A literature review by Gold explores sixty studies ($N = 6200$) examining parents' experiences with healthcare providers in the wake of perinatal death. Nurses were generally the most likely to provide emotional support after miscarriage, and doctors were typically rated as less supportive and helpful. Participants in one study in this review describe physicians as cold and neutral. In terms of specific behaviors that left a lasting impact, patients were dissatisfied with care when healthcare providers avoided the topic of miscarriage or avoided interactions in the days following the loss. Thoughtless and inconsiderate comments also left lasting impressions. Most frequently, parents who experienced perinatal loss expressed dissatisfaction with the lack of emotional support from their healthcare providers. When caregivers expressed emotional support, it was deeply appreciated and remembered (Gold, 2007). When healthcare providers are willing to provide emotional support following miscarriage, there are clear benefits. When they fail to provide the necessary psychological resources, it can significantly impact quality of care.

One of the major goals of genetic counseling, particularly in the prenatal setting where testing is largely preference-based, is the facilitation of informed decision-making. In addition to general concern for clients' wellbeing, the issue of the lasting psychological effects of miscarriage pertains to the practice of genetic counseling because unresolved issues surrounding pregnancy loss can affect the complex decision-making process.

Typical prenatal genetic counseling sessions include obtaining a detailed family and pregnancy history. Given the prevalence of miscarriage, patients frequently reveal experiences of pregnancy loss during the process of genetic counseling. Additionally, recurrent miscarriage is a common indication for genetic counseling (Garrido-Giminez, 2015). Despite this relevance of miscarriage to the genetic counseling profession, no study has specifically examined genetic counselors' willingness and preparedness to provide thoughtful medical and emotional support following miscarriage. This gap becomes increasingly glaring given the fact that the field of genetic counseling is placing more importance on psychosocial counseling than ever before.

Given this, the goals of this study were to determine genetic counselors' understanding of the magnitude of the psychological and interpersonal effects that can follow miscarriage, as well as their preparedness to discuss these effects with patients. This study also aimed to identify the most pertinent barriers to engaging in more in-depth psychosocial discussions with patients who have experienced a miscarriage. In addition to assessing the perspectives of prenatal genetic counselors as a whole, the study aimed to identify key differences across various demographics and experience levels to determine what, if any, intervention for genetic counselors may be necessary.

Methods

Participants

Participants were recruited via the National Society of Genetic Counselors (NSGC) email Listserv. Genetic counselors who currently work in the prenatal setting and possess at least one year of experience in that setting were invited to participate in an

online survey. The recruitment email reached approximately 3,000 NSGC members. At the conclusion of the survey, participants ($N = 279$) were asked to provide their email address on a separate form if they would be willing to participate in a follow-up phone interview.

Instrumentation and Procedure

A survey instrument was developed to reflect the specific aims of the study. The survey was comprised of four main sections: general perspectives on the impact of miscarriage, perspectives on the genetic counselor's role in post-miscarriage psychosocial care, preparedness to discuss miscarriage, and barriers to psychosocial discussions about miscarriage. The questions were developed by a graduate student and reviewed and modified by a committee of genetic counselors and other investigators with qualitative and quantitative research experience. An interview guide was developed to collect qualitative data to supplement and enhance the survey data (see Appendix II). The interview questions were informed by committee opinions on data that could not sufficiently be represented by quantitative data such as descriptions of mental processes and richer explanations of care barriers. This guide was also reviewed and modified by a committee of genetic counselors and researchers. A summary of the survey questions can be found in Table 2.

The survey was developed in Qualtrics, and was distributed to NSGC members via two email blasts. Participants were informed that completing the survey conferred their consent to participate. Upon completion, participants were asked to follow an independent link and provide their email address if they wished to receive a $10 Amazon

gift card for participation. This information was not linked to survey responses. The gift cards were distributed via email. At completion of the survey, participants were also asked if they would be willing to be contacted for a phone interview. Those who responded affirmatively were able to follow a link to a Google form and provide their email address and phone number. This information was not linked to survey responses. Semi-structured phone interviews were coordinated and scheduled via email. Interviews were audio recorded and transcribed.

Analysis

Transcripts were labeled with numbers, and any identifying words or phrases were removed. Transcripts were coded iteratively by a single coder using the analysis software MAXQDA. Emerging themes from the first several transcripts were used to generate the codebook. As new themes emerged, new codes were generated and applied to all transcripts. Interviews were conducted until saturation was reached and no new themes appeared to emerge. Survey data were analyzed using Microsoft Excel and IBM SPSS. Descriptive analyses were performed for each survey measure, and t-tests were performed to analyze differences across demographic groups. Correlational analyses were also utilized to explore correlations across variables.

Results

Survey Results

279 survey responses were collected. After removing responses that were more than 90% incomplete, 232 responses remained. Responses of individuals who did not

meet inclusion criteria (they either did not work in the prenatal setting or possessed less than one year of experience) were removed. Remaining responses from 200 participants were analyzed.

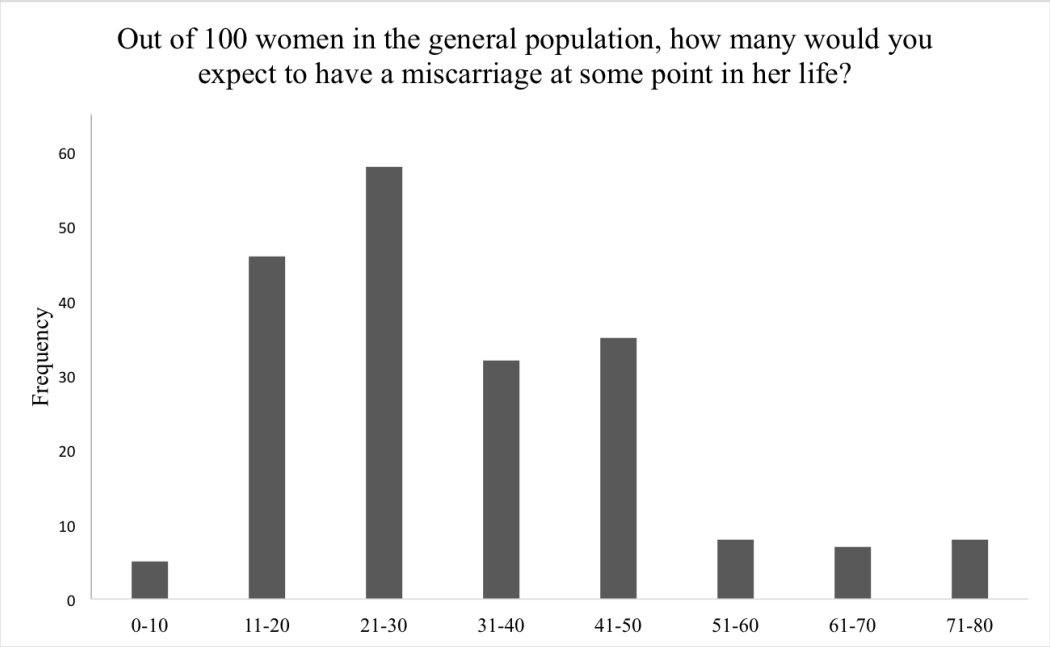
Demographics

The majority of the sample was female (185/200, 92.5%), white (175/200, 87.5%), and possessed 0-5 years of experience in genetic counseling (132/200, 66%). 18% of respondents possessed 6-10 years of experience, 8.5% possessed 11-15 years of experience, and 7.5% possessed more than 15 years of experience. Most participants had no living children (130/200, 65%). More detailed demographic information can be found in Table 1. This demographic makeup is in some ways comparable to the makeup of the genetic counselor population. The 2018 NSGC Professional Status Survey reports that 95% of American and Canadian genetic counselors are female and 92% are white. 51% of surveyed genetic counselors graduated from a genetic counseling training program after 2010, so the study sample is marginally less experienced than the general genetic counselor population.

Descriptive Statistics

Participants estimated how many out of 100 women in the general population they would expect to experience a miscarriage at some point in their life (the current reported estimate is 20-30%). Estimates ranged from 3 to 80. The median response was 30. The mean response was 34.9 with a standard deviation of 16.8. The distribution of responses is shown in Figure 1. Responses did not correlate significantly with years of experience

in genetic counseling, but there was a trend such that counselors with more years of



experience gave lower estimates (r = -0.126, p = 0.078).

Survey questions and mean responses are summarized in Table 2. On average, responses reflect the belief that miscarriage is highly significant. For the purpose of this analysis, a response in the range of 5 to 7 on the 7-point Likert scale is considered high significance/impact.

In regards to the overall significance of miscarriage to a person's life, 95% rated the significance as high (M = 5.96, SD = 0.88). The impacts of miscarriage upon one's partner and upon the relationship were rated generally highly, with 76.5% and 76% of responses, respectively, in the high range (M = 5.11, SD = 1.21 and M = 5.12, SD = 1.09,

Figure 1: Distribution of Miscarriage Prevalence Estimates

respectively). Women who have not experienced a miscarriage rated the impact of miscarriage upon both a woman's partner and upon the relationship higher than did women who have experienced a miscarriage (t = -2.28, p = .031 and t = -2.02, p = .045 respectively). There was a significant negative correlation between years of experience

and the rating of partner impact; as years of experience increased, partner impact rating decreased (r = -0.141, p = 0.048).

The impact of miscarriage upon a subsequent pregnancy was generally rated highly. 95% of respondents rated the impact of miscarriage upon *feelings* about a subsequent pregnancy as high (M = 6.34, SD = 0.87). 90.5% of respondents rated the impact of miscarriage upon *decision-making* during a subsequent pregnancy as high (M = 5.85, SD = 0.94). Women rated the impact of miscarriage upon both feelings about a subsequent pregnancy and decision-making during a subsequent pregnancy higher than did men (t = -2.34, p = .031 and t = -3.00, p = .010, respectively). However, it is important to note that only 13 men were included in analysis, so these results may be biased.

For analysis, the responses "somewhat agree," "agree" and "strongly agree" were collapsed into a single "agree" index. 94.5% participants agreed that miscarriage can cause depressive symptoms (M = 1.49, SD = 0.64). 90.5% of participants agreed that discussing the psychological impact of miscarriage is important in a genetic counseling session (M = 2.18, SD = 0.97). 86.5% of participants agreed that discussing the psychological impact of miscarriage is part of their job (M = 2.37, SD = 1.20).

Overall, participants report that they are prepared to discuss multifaceted issues of miscarriage. 97.5% of participants reported feeling at least somewhat prepared to discuss the various biological causes of miscarriage (M = 1.75, SD = 0.86 on a 7-point scale, 1 indicating that the participant strongly agrees that they are prepared). Women with a history of miscarriage more strongly agreed that they felt prepared to discuss the biological causes of miscarriage than did women who have not experienced the loss of a

pregnancy (t = -1.95, p = .05). Additionally, women with at least one living child more strongly agreed that they felt prepared to discuss the biological causes of miscarriage than did women with no children (t = 2.95, p = .004).

90% of participants felt at least somewhat prepared to discuss the possible short-term psychological effects of miscarriage, and 70.5% reported such preparedness regarding the long-term effects. 52.5% of participants reported at least being somewhat preparedness to discuss the relationship problems that can follow a miscarriage. Similarly, 53% reported being at least somewhat prepared to ask a couple about their relationship following a miscarriage.

There were significant correlations between years of experience in genetic counseling and every preparedness measure, as well as several barrier measures. The details of the correlations between years of experience and various measures can be found in Table 3.

The seemingly most prevalent barrier was that the patient did not want to discuss it, which received a mean rating of 4.96 (SD = 1.43). The next most prevalent was a lack of time, for which the mean score was 4.24 (SD = 1.75). Lack of training was reported as a relatively low-prevalence barrier, with mean scores of 2.87 and 2.48 for a lack of training in school and a lack of training from an employer, respectively (SD = 1.80 and 1.81). Moderate barriers were the desire not to upset the patient (M = 3.41, SD = 1.74) and the belief that the topic seemed irrelevant (M = 3.37, SD = 1.84). Two barriers were significantly negatively correlated with years of experience: ratings for the desire not to ask invasive questions and the desire to not upset the patient decreased as years of experience increased (r = -0.169, p = 0.018 and r = -0.159, p = 0.026, respectively).

Interview Results

Below is a summary of the major emerging themes from 25 interviews conducted with survey participants, along with quotations illustrating said themes. All interview participants were female, and currently work in the prenatal setting.

Diverse Client Responses

Participants repeatedly acknowledged the diversity of client responses to pregnancy loss.

"I think every patient that I see…they have very different takes. It's very hard to know or predict where they're going to be, I think, in their journey and their processing of their history."

"The reactions are so across the spectrum. I've come to never assume that a patient's reaction is going to be a certain way."

Follow-Up Discussions

Most participants (22/25, 88%) responded that they have been in a situation where a patient revealed that they experienced a miscarriage that the genetic counselor was not aware of before the session. These participants were asked what, if any, follow-up questions they ask when a patient reveals that they have lost a pregnancy. The most common responses were to ask the gestational age at the loss (17/22, 77%) and whether any testing was done to determine a cause (17/22, 77%). Nine participants (41%) reported that they would offer condolences:

"Almost always I will say, "I'm sorry for your loss," and see how they take me saying that."

Nine participants (41%) reported that they would ask a psychosocial follow-up question:

"Usually after I am taking history and I usually start with the pregnancy history to learn about those kinds of things, I always mention something like, 'I know that's difficult to go through, how have you been doing emotionally?'"

Less commonly mentioned follow-up questions included asking whether the loss was with the current partner or a different partner (5/22, 23%), whether a surgical procedure was necessary after the miscarriage (3/22, 14%), and whether there is a family history of miscarriage (1/22, 5%).

Personal History

Participants were asked if they would be comfortable answering a personal question about miscarriage, and all responded affirmatively. Six participants (24%) reported having experienced a miscarriage and 19 participants (76%) lacked a personal history. Participants with a personal history of miscarriage tended to report that this history had in some way affected their practice:

"Prior to experiencing those losses myself, I will admit that I probably didn't understand the emotion that people can feel after a loss. And then having gone through it myself, I can appreciate those emotions and those feelings and that attachment more than I appreciated before."

"I didn't really understand how [a first trimester loss] could be so difficult. And even saying that sounds horrible now, but having experienced one, I feel like now I understand better how it can be so difficult because you get so attached so quickly and you physically are already showing symptoms."

Several themes arose from the responses of those who had not personally experienced a miscarriage. One of these was to admit an inability to fully understand the experience of miscarriage on an emotional level:

"*Sometimes I worry if I'm too jaded about it. I see it all the time and I've never experienced it, so it's almost just a normal thing that happens."*

"From a head perspective I understand…but there's kind of an ache there where I haven't experienced the heart version."

Other participants reported that lacking a personal history of miscarriage protects them from countertransference:

"Because I've never had a personal experience with pregnancy loss, I don't think I have any preconceived notions about how I'd feel during that situation, so I think the countertransference won't be there in the sessions, because I'm not thinking 'Well, when I was in that situation I felt this way, so I think my patient probably feels the same.'"

"If I had just had a miscarriage and so had she... I don't know. Would that put me into reliving trauma?"

Barriers

Time was the most frequently reported barrier to engaging in more in-depth psychosocial discussions about miscarriage with patients:

"There's never enough time."

"In the average clinic day, you could have four or five patients, so being able to actually delve into a topic like that and give it it's proper time isn't always possible."

Since miscarriage is not always the primary indication for speaking with a prenatal genetic counselor, the second most prevalent cited barrier was the necessity to discuss topics related to the patient's indication for referral:

"We need to talk about the things that you were actually sent to me for."

Some participants cited the presence of other individuals as a barrier to engaging in more in-depth discussions:

"Talking about it with me in front of their spouse may feel uncomfortable."

"There's usually moms or sisters or grandparents with them… and I don't know that families always want to discuss openly with their extended family their feelings about their history of loss."

Several participants expressed a belief that genetic counselors simply are not comfortable or prepared to engage patients in discussions about pregnancy loss:

"Genetic counselors aren't asking the questions because they don't know what to do with the answers."

"If he or she doesn't feel like it's something that they understand well enough to really delve into, it's easy not to go there if you don't feel confident in how you'd have that discussion with a patient."

"We have counselors who aren't even comfortable working with [intrauterine fetal demise] or losses because they don't like talking about babies who've passed."

In that same vain, several participants expressed a desire for ongoing training for genetic counselors in how to treat the topic of miscarriage:

"I think downstream it would be great to see some more guidance or instructions for genetic counselors in this area."

"I do think that most genetic counseling programs do a fabulous job in the rudimentary elements of crisis counseling, including for pregnancy loss, but having a class here or there whenever you may have graduated, that's not nearly enough."

Participants explained that the historical cultural "taboo" nature of discussing miscarriage in depth can pose a barrier in genetic counseling sessions:

"It's a topic that historically has been less discussed and less public."

"It's cultural norms. We don't talk about these things."

Several participants did not believe that, in most cases, psychosocial discussions about miscarriage were necessarily part of their job.

"Somebody who's had one miscarriage is probably not an issue for us to address. It's not somebody who's had multiple miscarriages… You just don't pay as much attention to it."

"By the time that we come into the picture…it's almost like the moment has passed, and it's not something that necessarily needs to be addressed at the time of our genetic counseling session."

Counseling Choices

Participants explained the factors that they actively consider when deciding whether or not to engage a patient in a psychosocial discussion about their pregnancy loss:

"Some patients are really guarded and don't want to talk about it, so I don't usually push them on that."

"I tend not to really dig too deep unless it's something that they seem very emotional about."

"If it was very recent, if they had experienced a loss within the past few months as opposed to it being a year or two or three ago, if it was their only pregnancy, if they didn't have any healthy children, sometimes I'm a little bit more likely to delve into that a little bit more deeply."

"I dig more into that when there's a history of multiple miscarriages because that seems to be a scenario where patients have a little bit more to share as far as the psychosocial piece of it."

"I look to see how they present that information to me. If their body language changes, if their voice - whether the volume, the pace, the inflection - changes when they mention the miscarriage."

The Effect of Miscarriage on a Subsequent Pregnancy

Participants repeatedly acknowledged that a history of miscarriage can dramatically affect how a woman feels and behaves during a subsequent pregnancy:

"Miscarriage history robs them of some of that innocence around early pregnancy, of that joy of the first couple weeks, because they're waiting on pins and needles to get past the point where they miscarried before."

"I still firmly believe that even one loss is enough to change a patient's perception of pregnancy. One of the things I always say is 'miscarriage changes how you go about pregnancy.'"

The Male Partner's Perspective

Several participants stressed the importance of attending to the male partner's perspective on the history of pregnancy loss:

"I think the fathers often get left out of this conversation."

"My own partner struggled with the losses as well."

"I wish there were more resources for men…I've had instances where I've looked for resources geared towards men and I've had such a hard time finding them."

Discussion

This study aimed to explore a seldom-studied aspect of prenatal genetic counseling practice: genetic counselors' perspectives on the psychosocial issues and discussion surrounding miscarriage. Quantitative survey data from 200 genetic counselors were supplemented with qualitative interview data from a subsample to obtain a richer understanding of this question.

At first glance, survey data seem to suggest that genetic counselors have a strong appreciation for the psychosocial impact of miscarriage, and see themselves as well prepared to discuss it. An overwhelming majority of participants agreed that miscarriage is a highly significant event that can impact her partner, the relationship, and feelings and decision-making during a subsequent pregnancy. However, the data introduce a few subtle contradictions. While over 85% of participants at least partially agreed that a psychosocial discussion about miscarriage is important to a genetic counseling session

and falls into the purview of their job, the barrier "It doesn't seem relevant" was rated moderately, with an average score of 3.37 out of 7 (7 being a barrier that frequently stops the discussion). If genetic counselors understand the impact of miscarriage upon a subsequent pregnancy and believe that addressing this impact is an important part of their job, one might expect ratings of irrelevance to be lower.

This discrepancy may have several origins, one of which is the general limitations of this study. In an online survey setting, successive questions may be rushed through without significant consideration or deliberation. Additionally, as most genetic counselors are aware that psychosocial counseling is an important tenet of their career, responses may have been influenced by social desirability. This could explain the overwhelmingly high significance scores. Another limitation is the fact that self-report descriptions of genetic counseling practice quite rarely reflect reality. Studies have demonstrated that even when genetic counselors report placing a strong emphasis on psychosocial counseling, direct observations of their counseling say otherwise [citation].

This contradictory survey result may however be caused by a more subtle decision-making process, which the qualitative data helped to clarify. Approximately 1/3 of the interview participants reported that they would automatically ask a psychosocial follow-up question when a patient revealed a miscarriage. The other participants described a more subtle approach when deciding whether or not to engage in a more in depth psychosocial discussion. They might look for "red flags" such as multiple miscarriages, a late miscarriage, or a very recent miscarriage. They also cited body language, word choice, and tone of voice as indicators of whether this was an appropriate time to pursue a more psychosocial discussion. In general, these counselors described a

process by which they determined whether a patient wanted to talk about their miscarriage. If they determined that the patient wanted to talk about it, it was pursued, and if the patient was more guarded, it was skipped. This attitude is reflected in the survey data as well; the highest prevalence barrier was "The patient didn't seem to want to talk about it." This introduces a more philosophical genetic counseling question. Is the role of a genetic counselor to only talk about what the patient wants to talk about, or to occasionally challenge a patient to think and talk about things that may be difficult, but will ultimately be important to the genetic counseling process and to their patient's adaptation?

As one interviewee so eloquently expressed, "it's easy to assume that they're okay." That is, after seeing possibly hundreds of patients who show indications that they have adapted well to a pregnancy loss, it is easy to assume that every patient with a pregnancy loss history that would not necessarily send up psychosocial red flags is adapting well and not in need of a psychosocial discussion or intervention. One could argue that it is impossible to know how someone is adapting if the proper questions are not being asked. This study seems to suggest that genetic counselors may not be asking those questions, and instead may be relying on their assumptions.

Measures of preparedness somewhat differed between the qualitative and quantitative analysis. Lack of training from a graduate program and from an employer were relatively low-rated barriers on the survey. Interview participants, however, almost universally expressed a desire for more training in this area, both in graduate programs and throughout the career. This difference could stem from the fact that while survey questions probed the respondent's personal preparedness, interview respondents often

cited the unpreparedness of their colleagues to delve into these issues. Survey participants may have been influenced by social desirability and were thus unwilling to admit to being unprepared for some scenarios, or they may be unaware of the areas in which they are unprepared. The extremely varied estimates about miscarriage prevalence indicate that genetic counselors may be less informed about miscarriage than they believe.

Furthermore, every preparedness measure correlated with years of experience in genetic counseling, such that more experienced genetic counselors more strongly agreed that they were prepared for various aspects of this conversation. Counselors with more years of experience tended to rate the barriers of not wanting to be invasive, not wanting to upset the patient, and not being trained by their employer as less pervasive. This demonstrates that more experience and exposure to the topic of miscarriage may itself improve preparedness for these discussions.

This study has several limitations in addition to those noted above. One of these is the survey instrument. While the survey was developed and refined to meet the goals of the study, it is not a validated survey instrument. Development of a validated instrument to address the study questions and related questions may be warranted. Another limitation is the possibility for self-selection bias. The study population may only represent genetic counselors with strong feelings about the topic of miscarriage, who were thus more likely to volunteer. Furthermore, the subset of these participants who volunteered to be contacted for an interview probably represents the most opinionated faction of the study population, rather than a representative sample. The fact that 12.5% of all survey participants have experienced a miscarriage versus 24% of interview participants is illustrative of this pattern. Demographic data (except for gender) was not collected from

interview participants, so it was not possible to compare the characteristics of this subset to the larger study population. The homogeneity of the genetic counselor population (largely female, white, and relatively new to the field) can also make analyses biased.

Further studies are warranted to determine more objectively how the conversations between genetic counselors and patients with a history of miscarriage actually unfold, and to determine whether genetic counselors are truly prepared to handle the myriad of psychosocial issues that may arise. The development of training interventions to be implemented during graduate education and throughout the career may also be warranted. A workforce of prenatal genetic counselors who are more prepared to discuss miscarriage with their patients may ultimately lead to improved genetic counseling outcomes and improved patient adaptation.

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Appendix I: Tables

Table 1: Survey Demographics

	***N* (%)**
Gender	
Female	185 (92.5)
Male	13 (6.5)
Did not disclose	2 (2)
Ethnicity	
White/Caucasian	175 (87.5)
Black/African America	1 (0.5)
Asian/Pacific Islander	4 (2)
Hispanic/Latino	2 (1)
Other	3 (1.5)
More than one ethnicity	15 (7.5)
Number of living children	
0	130 (65)
1	19 (9.5)
2	39 (19.5)
3	12 (6)
Years of experience	
0-5	132 (66)
6-10	36 (18)
11-15	17 (8.5)
16-20	8 (4)
21-25	2 (1)
26-30	3 (1.5)
Did not disclose	2 (1)
Personal history of miscarriage	
Yes	25 (12.5)
No	173 (86.5)
Did not disclose	2 (1)

Table 2: Mean Survey Responses

	M (SD)
General Perspectives[1]	
How significant of an event is miscarriage in a person's life?	5.96 (0.88)
In general, how much does miscarriage impact a partner's life?	5.11 (1.21)
In general, how much does miscarriage impact the relationship between a woman and her partner?	5.12 (1.09)
In general, how much does miscarriage impact a woman's feelings about a subsequent pregnancy?	6.34 (0.87)
In general, how much do the effects of miscarriage influence decision-making in a subsequent pregnancy?	5.85 (0.94)
To what extent do you agree that...[2]	
Miscarriage can cause depressive symptoms.	1.49 (0.64)
Discussing the psychological impact of miscarriage is important in a genetic counseling session.	2.18 (0.97)
Discussing the psychological impact of miscarriage is part of my job.	2.37 (1.20)
I feel prepared to...[2]	
Discuss the various biological causes of miscarriage.	1.75 (0.86)
Discuss the possible short-term psychological effects of miscarriage.	2.22 (1.12)
Discuss the possible long-term psychological effects of miscarriage.	2.96 (1.47)
Discuss the relationship problems that can follow miscarriage.	3.62 (1.64)
Ask couples about their relationship following a miscarriage.	3.67 (1.76)
Barriers[3]	
There isn't time to discuss it.	4.23 (1.75)
I wasn't trained to discuss it in school.	2.87 (1.80)
I wasn't trained to discuss it by my employer.	2.48 (1.81)
I don't want to upset my patient and/or her partner	3.41 (1.74)
I don't want to ask invasive questions.	2.88 (1.70)
The patient didn't seem to want to talk about it	4.96 (1.43)
It doesn't seem relevant.	3.37 (1.84)

[1] Likert-type score ranging from no impact/significance (1) to high impact/significance (7)

[2] Likert-type score ranging from strongly agree (1) to strongly disagree (7)

[3] Likert-type score ranging from "This never stops me" (1) to "This frequently stops me" (7)

Table 3: Years of Experience Correlational Analyses

Correlate with Years of Experience	Correlation coefficient (*r*)	*p*-value
Miscarriage prevalence in the general population	-.126	.078
Preparedness to discuss biological causes of miscarriage	-.202	.004*
Preparedness to discuss short-term psychological effects	-.170	.017*
Preparedness to discuss long-term psychological effects	-.137	.050*
Preparedness to discuss relationship problems	-.186	.009*
Preparedness to ask a couple about their relationship	-.183	.010*
Significance of miscarriage	.029	.689
Impact upon partner	-.141	.048*
Impact upon relationship	-.024	.733
Impact upon feelings about a subsequent pregnancy	.135	.059
Impact upon decision-making in a subsequent pregnancy	.064	.375
Barrier: Time	-.035	.627
Barrier: Not trained in school	-.120	.094
Barrier: Not trained by employer	-.192	.007*
Barrier: Don't want to upset patient	-.159	.026*
Barrier: Don't want to be invasive	-.169	.018*
Barrier: Patient unwilling to discuss it	.097	.177
Barrier: It seemed irrelevant	-.015	.833

* Significant at the .05 level

Appendix II: Interview Guide

Verbal consent: This interview is part of a research project exploring genetic counselors' perspectives on and practices surrounding the psychological impact of miscarriage. Your participation is completely voluntary. You may choose not to answer any question and I can turn off the recorder at any time if you do not want your response to a particular question recorded. If you decide that you no longer wish to participate, you may ask me to stop the interview at any time. This interview should take approximately 15-20 minutes and will include questions about your professional and personal experiences with the topic of miscarriage.

The interview will be audio recorded and transcribed. I will not use your name or other personal identifiers during the interview and ask that you not use your name or others' names during the interview. The audiotape will not be labeled with personal identifiers. We will use code numbers to refer to specific interviewees. The audio and transcript files will be kept in password-protected folders on a password-protected computer. The recording will be deleted once the transcripts have been completed. Excerpts from the interview may be included in my thesis. For the final reports or publications, I will ensure that any names of people, places, and other identifying words have been removed to decrease the likelihood that any excerpts would be identifiable.

Feel free to contact me, my academic advisor William Klein, or Lori Erby, the director of my program, with any questions regarding participation. To thank you, after the interview is complete, I will email you a $10 Amazon gift card, in addition to the gift card you received for completing the survey. All of your answers will be kept confidential.

Discussion of Miscarriage

I'm hoping you could describe for me the last time you saw a patient who had experienced a miscarriage.

This question is to elicit a narrative that will hopefully hit on the following points. If any points are not covered, they will be asked as follow-up questions:

How long ago was the miscarriage?

How far along was the pregnancy?

Was a cause determined?

Was the patient distressed about the miscarriage?

Was a partner present for the conversation? (If not, another companion?)

Have you ever been in a situation where a patient revealed a history of miscarriage that you did not know about ahead of time?

- *When the patient revealed her miscarriage history, what follow-up questions did you ask?*

What factors were you thinking about when deciding whether or not to engage in a detailed discussion about the miscarriage?

How frequently do you find yourself following up on psychosocial issues related to miscarriage? Does it come up often? When it comes up, how much time do you spend on it?

Have you ever referred a patient for follow-up psychological care following a miscarriage?

- *Or support groups?*
- *If so, how did you know it was necessary?*

Personal History

Do you feel comfortable answering a personal question about miscarriage?

- Remind participants that they are under no obligation to discuss anything that makes them uncomfortable, and encourage them to let me know if they experience distress

If **no**, skip this section

If **yes**:

Have you ever personally experienced a pregnancy loss?

If **yes**:

How old were you? How far along in the pregnancy? Was a cause determined?

Do you feel that the experience has affected the way you talk about miscarriage with your patients? What effect has it had? Ever disclosed to patient?

Thank you very much for helping me understand this more. I know this can be difficult to talk about.

If **no**:

Reflect on how lacking a history of miscarriage might affect clinical practice. Does it matter at all? How so?

Barriers

What do you see as the most prevalent barriers to discussing the psychological impact of miscarriage with patients? How do you think we can overcome these barriers?

Final Thoughts

Can you think of anything else that you would like me to know about your experience working with patients who have had a miscarriage?

Curriculum Vitae

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Education

Johns Hopkins University – Baltimore, MD **September 2016 to Present**
- Candidate for ScM in Genetic Counseling
- Trainee of the National Human Genome Research Institute (NHGRI), National Institutes of Health (NIH)

New York University – New York, NY **September 2012 to May 2016**
- Bachelor of Arts in Psychology with a dual minor in Genetics and Science & Society
- Presidential Honors Scholar, graduated with honors in Psychology, 3.9 GPA

Genetic Counseling Experience

Clinical Rotations

Kennedy Krieger Institute, Neurogenetics – Baltimore, MD **Autumn 2018**

Johns Hopkins Clinical Cancer Genetics and Prevention – Baltimore, MD **Autumn 2018**

Johns Hopkins Internal Medicine – Timonium, MD **Spring 2018**

NIH, NHGRI, Medical Genomics and Metabolic Genetics Branch – Bethesda, MD **Winter 2018**
- Counseled families affected by methylmalonic and propionic acidemia during their participation in NIH research

Johns Hopkins Hospital: Division of Maternal-Fetal Medicine – Baltimore, MD **Autumn 2017**

Walter Reed National Military Medical Center – Bethesda, MD **Spring 2017**
- Counseled children, families, and adults affected by and at risk for genetic conditions
- Gained exposure to the complexities of genetic testing in the military setting

Mercy Medical Center: Center for Advanced Fetal Care – Baltimore, MD **Winter 2017**
- Counseled high risk prenatal patients and developed counseling skills through professional supervision
- Gained experience in an inner city setting, working with patients of varying socioeconomic and literacy levels

Other Experience

GeneDx – Gaithersburg, MD **Summer 2018**
- Gained experience in the roles of a laboratory genetic counselor, including report writing, clinical abstracting, variant classification, and customer service

Hawaii State Department of Health, Genetics Section – Honolulu, HI **Summer 2017**
Summer Department Intern
- Developed web content for the Hawaii Department of Health's Newborn Screening Program
- Assembled information and resources on Zika virus specific for the Hawaiian population

Genetic and Rare Disease Information Center (GARD) – Rockville, MD **Autumn 2016**
Information Specialist Intern
- Connected individuals with information and resources regarding rare diseases including referrals to healthcare providers, support groups, online resources, and general genetic information
- Created web content for GARD's website, including information intended for the general public